

## Research Participant privacy notice

This Notice is for people who are participating in, or have been invited to participate in, an academic research project being undertaken by UoH students and/or staff ("UoH researchers"). You should read this Notice alongside the participant information sheet provided to you by UoH researchers.

### Questions

If you have any questions or concerns about participation in a research project and how your data will be collected and managed for the project, please contact the UoH researchers using the details in the participant information sheet. If you have any other questions or concerns about UoH's processing of information for research purposes and the content of this privacy notice, please contact the UoH Data Protection Officer (DPO): Email: [dataprotection@hull.ac.uk](mailto:dataprotection@hull.ac.uk) Telephone: 01482 466594 Address: University of Hull, Cottingham Road, Hull HU6 7RX

### About this notice

In this Notice "UoH", "we", "our" and "us" refers to the University of Hull. As a result of your participation in our research, UoH will hold your "personal data", i.e. information in a form that identifies you as individual [often referred to as "data" in this Notice]. UoH is the data controller of the information it collects and processes as described in this Notice. This means that it has the core legal responsibility to safeguard the information and ensure it is processed lawfully. The law is set out in the EU General Data Protection Regulation (called "GDPR") and a new UK law, the Data Protection Act 2018. In particular UoH must:

- Take steps to ensure that the data it processes is accurate and up to date;
- Give you clear information about its processing of your data, in one or more privacy notices like this one and the participant information sheet (referred to together in this section as a "Privacy Notice");
- Only process your data for specific purposes described to you in a Privacy Notice, and only share your data with third parties as provided for in a Privacy Notice; and
- Keep your data secure.

Information about your data protection rights as a data subject is set out in the second section of this Notice.

### Your rights as a data subject and how to exercise them

Under the data protection laws, you have a number of rights in relation to our processing of your data. In summary these are: • Right to request access to your data as processed by UoH and information about that processing • Right to rectify any inaccuracies in your data, until the withdrawal time for consent, stated in the Participant Information sheet, has expired.

- Right to request erasure of your data from our systems and files
- Right to place restrictions on our processing of your data
- Right to object to our processing of your data
- Right to data portability: where we are processing data that you have provided to us, on the basis of consent or as necessary for the performance of a contract between us, you have the right to ask us to provide your data in an appropriate format to you or to another controller.

**Exceptions:** Most of these rights are subject to some exceptions or exemptions. In particular, there are limits on your right to restrict our processing or erase your data where this would impact adversely on the integrity and value of academic research, although as explained above, we will usually agree to withdraw your data from studies where this is possible.

If you would like to exercise any of your rights as outlined above, you can contact the DPO as above or visit the Data Protection page on our website

<https://www.hull.ac.uk/choose-hull/university-and-region/key-documents/data-protection.aspx> We will always aim to respond clearly and fully to any concerns you have about our processing and requests to exercise the rights set out above. However, as a data subject, if you have concerns about our data processing or consider that we have failed to comply with the data protection legislation, then you have the right to lodge a complaint with the data protection regulator, the Information Commissioner:

Online reporting: <https://ico.org.uk/concerns/>

Email: [casework@ico.org.uk](mailto:casework@ico.org.uk) Tel: 0303 123 1113

Post: Information Commissioner's Office Wycliffe House Water Lane Wilmslow Cheshire SK9 5AF

### How and why we will collect your personal data

We would like you to participate or continue your participation in the research being carried out by UoH researchers. "Research" is a form of disciplined enquiry which aims to contribute to a body of

knowledge or theory. The UoH researchers carrying out the research may be undergraduate or postgraduate students (working under appropriate staff supervision), UoH staff or a combination of staff and students. The research may be carried out only by UoH researchers, or it may involve UoH researchers working in collaboration with researchers in other organisations. UoH researchers will provide you with a participant information sheet setting out details of the particular research study. This will explain the purpose of the research, the criteria for participating (i.e. why we think you are a suitable person to be involved), what is involved in participation (i.e. what we will ask you to do) and which data we will be collecting or generating and retaining in the course of the research project. It will also explain how we will use your data in our research outputs, and let you know if your data will be shared in an identifiable form with any third parties, such as collaborators from other organisations. In addition to data we collect from you or generate through interactions with you as part of the research activity, we will also hold your personal data within project management documentation (in particular participant agreements or consent forms) and records of any communications with you through email or letter.

### **How we look after your data**

UoH will hold the data we collect about you in hard copy in a secure location and on a UoH password protected secure network where held electronically.

Except where it has been anonymised, your personal information will be accessed and used only by appropriate, authorised individuals and when this is necessary for the purposes of the research or another purpose identified below. This may include giving access to UoH staff or others responsible for monitoring the study, who need to ensure that the research is complying with applicable regulations. The participant information sheet will provide further information about any measures specific to the research project which will be used to control access to your data or minimise the use of your data in an identifiable form.

### **Further uses of your data**

We will usually only use your identifiable data for the purposes of the specific research project, and for associated monitoring activities carried out by authorised individuals with responsibility for those activities. If we intend to use your personal data in any other related research project or for research over a longer period, this will be explained in the participant information sheet. Where the research results in your data being anonymised and forming part of a statistical research dataset, we may store it in our research archive and use it (in that anonymised form) for future research.

### **Sharing your data**

UoH researchers will have access to your personal information in identifiable form as described in the participant information sheet. If it is necessary for the purposes of the research project for other people to have access to your personal information in identifiable form, this will also be explained in the participant information sheet. This may be the case if we are conducting the research in collaboration with other organisations (e.g. another university or an NHS trust), if we need to use an external service (e.g. transcription) or if our work is monitored or by another organisation, such as a separate organisation providing funding for the research or a collaborator organisation with its own requirements. If we do share your data in this way, there will be arrangements in place to ensure that the external partner keeps your data secure and only processes it for conducting research.

### **Retention of your data**

The participant information sheet will explain the length of time for which we expect to keep your data in identifiable form, and why we retain it for this period. This will include information about the duration of the project and whether it is necessary to keep data in identifiable form for the whole of that period. It will also inform you of any intention to keep identifiable data for a longer period, for example where there is an intention to link this research to outputs from another project, or to project changes to factors or outcomes over time. In setting retention periods, UoH researchers will take account of any need to retain data in identifiable format to enable them to verify their research outputs. For example, this may occur if their results are queried before or after publication, during peer review or where their research is subject to assessment or examination. However, UoH researchers will set appropriate retention periods to ensure that data is not kept in identifiable form for longer than necessary to meet these requirements. Where longer retention periods are identified as appropriate, this will be kept under review to ensure that we only keep identifiable data where this is necessary for continuing research purposes. Appropriate security measures and access controls will be applied to personal data where a research project is complete and we are storing research data.

### **Legal basis for processing your data**

The law states that we can only process your personal data if the processing meets one of the conditions of processing in Article 6 GDPR. If we are processing your special category data for our activities, we must meet one of the conditions in Article 9 GDPR. Special Category data includes personal data which relates to your ethnicity, sex life or sexual orientation, health or disability, biometric or genetic data, religious or philosophical beliefs, political opinions or trade union membership. Under the data protection legislation we need to explain the legal basis for holding your data, i.e. which of these conditions apply. In general, where we are collecting and processing your personal data for the purposes of an academic research project the following conditions apply:

- Article 6.1(e) of the GDPR, i.e. our processing is necessary for the performance of a task carried out in the public interest. Research is a task that UoH performs in the public interest, as part of our core function as a university;
- Article 9.2(j) of the GDPR, i.e. our processing is necessary for research purposes or statistical purposes. This condition applies as long as we are applying appropriate protections to keep your data secure and safeguard your interests; these are described above in section x.

Consent is not generally the legal basis under the data protection legislation for use of your personal data for research. This is because we can only rely on your consent as the basis for processing data if we would always be able to act on a withdrawal of consent, by removing your data from our research project and outputs. Often we would not be able to do this in the context of a research project, as this could affect the validity and integrity of the research process and/or the outputs from the research. We do ask for your consent for your active participation in the research, and you can withdraw this consent at any time. For example, if we have asked you to take part in interviews, complete a questionnaire or undergo observation, you can pull out of these activities at any point. This consent to participation in the project does not mean that we are relying on your consent as the legal basis to the on-going use of your information through the course of the project and in the research outputs. If possible, where you withdraw from participation in this way we will also withdraw your data from the research project, but this will depend on the stage we have reached in the project and how your data has been used. We will not be able to withdraw all of your data from the study if this will have an adverse impact on the integrity and validity of the research, a cut off point for withdrawal will be stipulated in the Participant Information Sheet. Even if we withdraw from the study your data that has been collected or generated within the research project, we will usually need to retain copies of your data within the project governance documentation (e.g. records of consent forms and possibly some communications with you). This will be further explained within the Participant Information Sheet. However you may be asked for consent for specific uses of your data

### **When will you be asked for consent?**

- If we need to access information in your medical records for the purposes of the research, the law of confidentiality states that we can only do this with your consent. Once you have given consent, our ongoing use of this information is covered by the conditions in the data protection legislation as described above; Articles 6.1(e) and 9.2(j)
- If we intend to use your personal data in our research outputs in an identifiable way, we will only do this if you specifically consent to this activity. For example, we will ask for your consent to include your photo or your name in any research reports or other outputs, and for inclusion of any film footage of you in any film to be produced as an output of the research. You can withdraw this consent at any time prior to publication or broadcast. However, any refusal or withdrawal of this consent will not affect the on-going legal basis for the use of your data for the research itself, which is covered by the other conditions in the data protection legislation as described above.

The UoH researchers will ask you to sign a participant agreement. This will set out any consents that are being requested for specific uses of your data, and it will also ask you to confirm that you have been given access to this Notice.